

*Correspondence***Mothers' experiences: A missing puzzle piece in caring for children with autism spectrum disorder**Mohammadrasool Ghasemianrad ^a  | Reza Nematollahi Maleki ^b  | Shabnam Rasoulpoor ^{c*} 

a. Department of Nursing, School of Nursing and Midwifery, Kermanshah University of Medical Sciences, Kermanshah, Iran

b. Department of Community Health and Geriatric Nursing, School of Nursing and Midwifery, Tehran University of Medical Sciences, Tehran, Iran

c. Department of Psychiatric Nursing, School of Nursing and Midwifery, Urmia University of Medical Sciences, Urmia, Iran

*Corresponding author(s): Shabnam Rasoulpoor (MSc), Department of Psychiatric Nursing, School of Nursing and Midwifery, Urmia University of Medical Sciences, Urmia, Iran.

Email: sh.rasoulpour@gmail.com<https://doi.org/10.32598/JNRC.P.2312.1003>This is an open access article under the terms of the [Creative Commons Attribution-NonCommercial 4.0 License](https://creativecommons.org/licenses/by-nc/4.0/) (CC BY-NC 4.0).

© 2024 The Author(s).

To the Editor

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by impairments in social relationships, communication, and restricted and repetitive behavioral patterns [1]. In recent years, epidemiological studies have shown a rapid increase in the prevalence of ASD. According to the report from the Center for Disease Control and Prevention in the United States, the prevalence was estimated to be 1 in 59 individuals in 2014 and 1 in 54 individuals in 2016 among 8-year-old children [2].

ASD is a complex developmental condition that is accompanied by persistent challenges in social interaction, speech, and nonverbal communication, significantly affecting mother-child interactions [3]. One of the most significant concerns for mothers of these children is how to care for them. The exact cause of this disorder remains largely unknown, and lack of awareness about autism often leads to delayed recognition of the child's difficulties by families [4]. As a result, the golden time for early intervention may be missed, and life in society becomes more challenging for both these children and their caregivers. Additionally, these children require care and support from their families and community institutions from birth throughout their growth and development, making caregiving a stressful process for mothers. Therefore, caring for these children necessitates the adoption of specialized caregiving and parenting approaches [5, 6]. The literature review

indicates that the majority of studies conducted in the field of caring for children with autism have primarily been quantitative studies with a traditional intervention approach, focusing on the effectiveness of cognitive-behavioral therapy play therapy, storytelling therapy, supportive counseling, psychotherapy, and teaching coping skills [7-9]. While quantitative research methods have their benefits in many areas, they alone cannot provide a comprehensive examination of the deep dimensions of the phenomenon from the perspective of individuals' first-hand experiences [10].

On the other hand, mothers of children with ASD have diverse and unique experiences that cannot be fully captured by common quantitative research, making qualitative research highly valuable for a deep understanding and exploration of these real experiences [5]. Additionally, families with lifelong ASD require long-term intervention, education, and support. However, factors such as limited treatment and rehabilitation centers, a lack of credible family education, and limited support from mental health service providers have increased the pressure on caring for children with autism [11]. Given the unique characteristics of children with ASD and the critical role of mothers in their resilience and care, and considering that a significant portion of mothers' lives is dedicated to caregiving, their experiences are the best source of information for providing care for these children. There is a growing sense of the need for studies focused on designing and implementing a simple, cost-effective, and efficient care pro-

gram based on mothers' experiences, which can alleviate caregiver fatigue and enhance families' ability to cope with the condition [5].

A deep understanding of mothers' experiences in living with a child with autism can provide insight into the psychological well-being of mothers, their needs, and their challenges. This understanding can be valuable for all institutions and organizations involved, including counselors and policymakers in the field of family services and welfare organizations, in developing comprehensive and practical programs for the care of children with ASD. Therefore, developing interventions that align with mothers' experiences and are culturally appropriate can be highly effective.

Acknowledgements

Not applicable.

Authors' contributions

Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work: MG, RNM, SR; Drafting the work or revising it critically for important intellectual content: MG, RNM, SR; Final approval of the version to be published: MG, RNM, SR; Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved: MG, RNM, SR.

Funding

Self-funded.

Ethics approval and consent to participate

Not applicable.

Competing interests

We do not have potential conflicts of interest with respect to the research, authorship, and publication of this article.

Availability of data and materials

The datasets used during the current study are available from the corresponding author on request.

Using artificial intelligent chatbots

None.

References

1. Black D, Grant J. DSM-5® guidebook: the essential companion to the diagnostic and statistical manual of mental disorders. 5th ed. Arlington, VA: American Psychiatric Association Publishing; 2014. p. 201–215.
2. Baio J, Wiggins L, Christensen DL, Maenner MJ, Daniels J, Warren Z, et al. Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014. *MMWR Surveill Summ.* 2018;67(6):1-23.
3. Hodges H, Fealko C, Soares N. Autism spectrum disorder: definition, epidemiology, causes, and clinical evaluation. *Transl Pediatr.* 2020;9(Suppl 1):S55-S65.
4. Bessette Gorlin J, McAlpine CP, Garwick A, Wieling E. Severe Childhood Autism: The Family Lived Experience. *J Pediatr Nurs.* 2016;31(6):580-597.
5. Papadopoulos D. Mothers' Experiences and Challenges Raising a Child with Autism Spectrum Disorder: A Qualitative Study. *Brain Sci.* 2021;11(3):309.
6. Meirsschaut M, Roeyers H, Warreyn P. Parenting in families with a child with autism spectrum disorder and a typically developing child: Mothers' experiences and cognitions. *Res Autism Spectr Disord.* 2010;4(4):661-669.
7. Kurz R, Huemer J, Muchitsch E, Feucht M. Cognitive behavioral therapy for children with autism spectrum disorder: A prospective observational study. *Eur J Paediatr Neurol.* 2018;22(5):803-806.
8. Mitteldorf W, Hendricks S, Landreth GL. Play therapy with Autistic children. In: GL Landreth. *Innovations in play therapy.* London: Brunner Routledge; 2001. p. 257-270.
9. Jafarnejad S, Ebrahimi HK, Sohrabi S, Esmailian S, Iranmanesh S. Comparative Study of Painting and Storytelling Effects on attachment of Children with Autism. *Ann Romanian Soc Cell Biol.* 2021;25(3):8446-8453.
10. Safe A, Joosten A, Molineux M. The experiences of mothers of children with autism: managing multiple roles. *J Intellect Dev Disabil.* 2012;37(4):294-302.
11. DePape AM, Lindsay S. Parents' experiences of caring for a child with autism spectrum disorder. *Qual Health Res.* 2015;25(4):569-583.

How to cite this article: Ghasemianrad M, Nematollahi Maleki R, Rasoulpoor S. Mothers' experiences: A missing puzzle piece in caring for children with autism spectrum disorder. *J Nurs Rep Clin Pract.* 2024;2(2):121-122. <https://doi.org/10.32598/JNRCP.2312.1003>.